***What is Congenital Hypothyroidism*?**

Newborn babies that are born without a thyroid gland or born with a thyroid gland that cannot make enough thyroid hormone have **Congenital Hypothyroidism (CH)**.

***Congenital*** means that the condition is present at birth.

***Hypothyroidism*** means that the thyroid gland does not make enough of the necessary thyroid hormone,

**Thyroxine, also known as T4,** which the brain and the body needs for growth and development.

Newborn screening for Congenital Hypothyroidism (CH) is a routine practice in Canada and has enabled babies with CH to be diagnosed within the first 2 weeks of life. CH affects about 1 in every 4000 babies born in Ontario. CH used to be a major cause of mental disabilities in children. Newborn screening has made it possible to recognize the condition and start treatment quickly.

Development of the brain, as well as normal growth of the child, is dependent upon normal levels of thyroid hormone. Lifetime treatment with a daily thyroid pill will ensure your child’s normal brain and body growth and development.

The Pediatric Endocrinologist will monitor and adjust this dose for the first 3 years of your child’s life, and then they may transfer your child’s thyroid management to your family doctor.

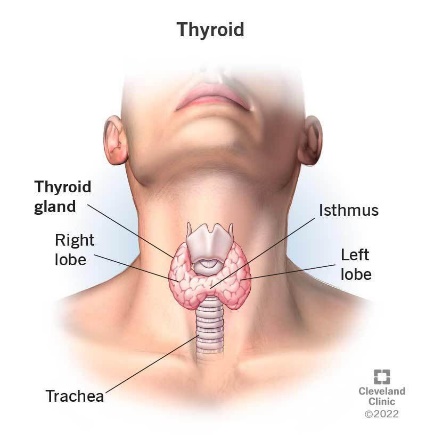
***What is the thyroid gland and what does it do?***

The thyroid gland is a butterfly shaped gland located in the front of your neck. The main hormone produced by the thyroid gland is **Thyroxine or T4** and no other part of the body can make this hormone. This thyroid hormone is needed by the brain and the body to grow and develop at a normal rate and to control your metabolism. Too much thyroxine makes the body work too fast, whereas too little thyroxine allows the body to slow down too much.

Another important hormone to know is **thyroid-stimulating hormone or TSH**. It is produced in the pituitary gland in the brain and it tells the thyroid gland to make Thyroxine or T4. These hormones act as chemical messengers to control growth and development of the body and brain.

You may think of these two glands working together like a thermostat and a furnace. The pituitary gland is the thermostat that senses when the body needs more T4. The pituitary gland “switches on” the production of T4 by sending TSH to stimulate the thyroid gland and being like a furnace, it produces heat or T4. So, the TSH stimulates the thyroid gland to produce T4, once the body has enough T4 to function properly, the thermostat or the pituitary gland shuts off production of TSH.

In Congenital Hypothyroidism, the pituitary gland senses that the body needs T4 so it sends the TSH to stimulate the thyroid gland to produce it. The thyroid gland cannot produce enough T4 for the body to function, however the pituitary gland doesn’t know that, and it keeps trying to stimulate the gland by sending more TSH. So when we check the blood levels of TSH and T4, we see that the level of TSH is very high and the T4 is very low. We will talk more about the blood tests further down in the handout



It is important for you to know that there is nothing you could have

done during your pregnancy to cause or prevent Congenital Hypothyroidism

***What causes Congenital Hypothyroidism or CH?***

The most common causes are:

* The thyroid gland does not develop normally during pregnancy, this is call ***dyshormonogenesis***
* The thyroid gland is not located where it should be in the neck, and does not function. This is called an ***ectopic gland***
* The thyroid gland is missing, this is called ***agenesis***
* Less commonly there is an inherited condition that prevents the thyroid gland from making thyroid hormone.

When the thyroid gland is poorly developed or absent, it will not produce thyroxine or T4.

***How is Congenital Hypothyroidism diagnosed?***

In Canada it is diagnosed at birth by taking a small sample of blood by heel prick from all newborns between day 2-and day 5 after birth. The blood sample is tested and a diagnosis is made when the TSH or Thyroid-Stimulating Hormone level is high. This tells the Endocrinologist that the pituitary gland is trying very hard to stimulate the thyroid gland to make thyroxine or T4 and that the thyroid gland is not responding to the TSH. If the TSH is high, the parents are informed and the findings are confirmed by repeating the blood test. Another test that may be done, is a thyroid scan, to see if the gland is present or if it is in the wrong place or if it is missing or absent

***How do we treat Congenital Hypothyroidism?***

It is easily treated by giving your baby a small pill every day that replaces the amount of thyroxine that the thyroid gland would normally produce. This pill is a synthetic form of thyroxine called ***Levothyroxine*.** In Canada it is sold under the brand names, ***Synthroid*,** and ***Eltroxin.***It is a safe medication that is identical to the body’s thyroxine, there are no side effects when the doses are within the correct range. The pills are small and colour coded so that the amount or strength of medication matches a colour.

The pills can also be cut in half to provide more dose possibilities

The best way to give the pill is to put the pill inside the baby’s cheek and feed them normally, either on the breast or with a bottle; the baby will swallow the pill naturally.

Other options include crushing the pill and placing all of the particles in the baby’s mouth with your clean finger. The pill can also be crushed and given to the baby in a small amount of formula or expressed

breast milk using an oral syringe, and then giving more liquid in the oral syringe to ensure the baby has receive all of the crushed particles. The pill does not dissolve easily even when it has been crushed

Do not prepare the crushed particles with a fluid more than 10 minutes in advance of giving it, it is not effective as a liquid and should be prepared only when you are ready to give it

You should not mix the crushed particles with a full bottle as the baby may not drink the entire bottle and could miss a portion of their dose

It is best if you can give the pill at approximately the same time every day when the baby feeds.

If your baby vomits within in 30 minutes of the dose it is best to give it again.

**It is very important that the pill is not given as a liquid form**, it is not effective when it is made into a liquid and stored as liquid. Ensure that you receive the pills from the pharmacists.

You may hear that you need to give the pill on an empty stomach, **we do not instruct parents to do this for a baby or young child. They need to take this medication with their feed**

***Why is it important to treat, what can happen?***

CH is easy to treat but if it is not treated the results are very serious. Thyroxine is a critical hormone that the brain and body need to grow and develop normally. When it is not available all the body systems slow down.

**If the baby does not receive daily thyroxine in the first 6 weeks of life their brain will not**

**grow and develop normally.**

**This will result in severe intellectual and developmental delays or disabilities**

These are some more of the negative effects of not having thyroxine available in the body

* The baby may be jaundiced when newborn
* The baby will be sleepier which will prevent the baby from responding and learning from their environment
* The baby will feed poorly which will result in poor weight gain and poor growth
* The baby will have a low body temperature
* The baby will be constipated due to a slow moving digestive tract
* The baby will have trouble breathing

Thanks to Newborn Screening programs across Canada, CH is quickly identified and treatment can be started early. Babies with CH who receive their daily thyroxine replacement can expect to develop normally and reach their full potential

***What about blood tests and doctor’s appointments?***

Babies grow very quickly and we have to keep up with their body’s needs for thyroxine. There will be times when the body needs more thyroxine or less thyroxine. The best way to determine this with children less than 3 years of age is by doing regular blood tests. You can expect that for the first year, blood tests can be as

frequent as every 2 weeks or every 3 months. This depends on the results and the changes to the dose that the Endocrinologist will make to ensure that your baby is getting the correct amount of thyroxine to support the brain and body’s development. So, there will be regular blood tests and changes to the dose quite frequently in the first 2-3 years. These blood tests are called FT4 (Free T4) and TSH.

There will be other times throughout your child’s development that there may be more need to do more frequent blood tests and change doses to match what the body needs. This can typically happen when a child is going through puberty. Sometimes it takes a few changes in the dose to ensure that your child has the correct amount of Thyroxine.

Regular blood tests are the best way to tell if your baby is getting enough thyroxine, however you may notice some behaviours that may make you suspect they need a blood test to check their thyroid levels.

At all times the Endocrinology team will ensure your child is safe and you are informed of results and dose changes promptly. You are very welcome to contact your Endocrine nurse if you have not heard about your results or sign up for CHEO’s MyChart for online access to this information and instruction from your Endocrinologist [mychart.cheo.on.ca](file:///D:\Thyroid\Congenital%20Hypothyroidism\Congenital%20Hypothyroidism%20BFraser%20Jan%202021.docx)

**What are the signs that your baby may be getting too much thyroxine (Thyroid medication)?**

* Feeding more but losing weight
* Irritable, restless, difficult to settle
* Not sleeping well
* Diarrhea (loose watery frequent stools)
* Warm to touch, sweaty
* Fast heartbeat

**What are the signs that your baby may need more thyroxine (Thyroid medication)?**

* Sleeping for long periods
* Quiet and content
* Cool mottled skin
* Dry skin and hair
* Poor feeding with poor weight gain

If you suspect your baby has any of these symptoms, please contact the Endocrine nurse and be prepared to have a blood test done to verify the TSH and T4 levels

Sometime CH may be temporary, in these cases the doctor may suggest your child stops Thyroxine treatment after the age of 3 then do a blood test to see if your child’s thyroid gland is working independently or not. If the results are normal, it may mean that your child no longer requires thyroxine and the Endocrinologist may check this a few more times to ensure the results remain normal. If the results are not normal it is very likely your child will always need to take thyroxine. When the decision is made to stop the thyroxine, it is very important that the blood tests are done at the time requested and that you contact the Endocrine nurse to ensure you know the results and the plan for your child’s medication

***Some more important things to know***

**There are no effective natural remedies or homeopathic treatments to replace daily Levothyroxine supplements. Levothyroxine is identical to the thyroxine hormone that the body produces.**

**Thyroxine cannot be made from plants or herbs and using “natural” products in place of Levothyroxine can present a serious risk to your child’s health**

**Soy products can interfere or prevent the thyroxine from being absorbed into the blood stream. It is advised to avoid soy-based formulas**

**As well Ovol can interfere with absorption of thyroxine, it is also best to avoid this product**

**Iron supplements and Biotin can also interfere with absorption, so if this is required try to give the two medications about 12 hours apart**

**Most parents are upset and worried when they first hear that their newborn baby has a health problem and will need daily medication for life. You can take comfort in knowing that by taking daily Levothyroxine and following medical direction for monitoring the thyroxine levels, your child will grow and develop like any other healthy child**

**If you have any concerns, please don’t hesitate to contact your Endocrine Nurse or Endocrinologist ☺**

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**Updated March 2023 B.Fraser RN**